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Disability statistics: an integral but missing (and misunderstood) component of development work

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1. Disability and development

In order to develop and evaluate policies and programs with the objective of improving the lives of their constituents, government rely on the availability of data in the form of statistics that are relevant, valid and reliable. Much of the information that is collected, normally through censuses and surveys, is intended for domestic purposes. There is however, within the international community, a long standing interest in making comparisons among countries not only to monitor how one's own country ranks against others, but to benefit from the experiences of others [Madans and Loeb, 2012]. In order for these cross-national comparisons to be meaningful, the information itself must be comparable across countries; the indicators used must address the same constructs and the data collection process must not introduce differences that would affect the relevance and validity of the comparisons. Many countries collect information on disability – and have been doing so for decades. Disability statistics however have long been plagued as examples of indicators where international comparisons are most difficult [Groce, 2006; Loeb & Eide, 2006; Me and Mbogoni, 2006; Mont, 2007a]. With respect to disability statistics that have been reported internationally, the fact that there are differences among countries does not mean that the data are not comparable but when these differences exhibit unexpected patterns, questions are raised. Observed differences illustrating the highest disability rates among the most developed countries and the lowest rates among the least developed countries are counterintuitive [Madans and Loeb, 2012]. A closer examination of how the data have been collected illustrates that there are major differences in approach, definition and methods [WHO/WB, 2011; Loeb & Eide, 2006]. This lack of comparability has hampered not only international uses of the data but also draws into question the usefulness of the information for domestic purposes.

The United Nations Convention on the Rights of Persons with Disabilities [UN, 2006] provides, for the first time within a human rights framework, specific articles that call for the international collection (Article 31) and reporting (Article 36) of statistical data on disability. In the absence of valid and reliable population-based data on disability it is not possible to monitor, over time, the effects of policies instigated that would promote the lives of persons with disabilities and ensure their participation in all aspects of life on an basis equal to those without disability. These data would provide the evidence that can be used to address whether countries have been successful, or the degree of their success, in meeting the general principles outlined in the Convention (Article 3) including the achievement of equalisation of opportunity and accessibility, among others. Monitoring the UN Convention

and other international initiatives such as the Millennium Development Goals (see: http://www.un.org/millenniumgoals/) depend on the production of quality and internationally comparable data – and these have been sorely lacking.

According to the bio-psycho-social model of disability, disability is understood as a complex concept involving the outcome of the interaction between a person (with a health condition) and that person's contextual factors (environmental factors and personal factors) [WHO, 2001]. People are not identified as having a disability based solely upon a medical condition, but rather are classified according to their functional capacity, along various domains including specific body functions and structure, limitations in basic activities (e.g., walking and seeing), and to the extent of their participation (or restrictions therein) in work, school, family life, and other social activities. Disability is conceived as a complex process that defies an “all or nothing” categorisation. Disabilities can be classified not only by type (mental, physical, sensory, or psycho-social), but also degree of severity, ranging from mild to severe.

2. Disability prevalence rates internationally

Several sources [see for example: Loeb & Eide, 2006; Mont, 2007a] report disability prevalence rates globally and each of these sources point to a characteristic divergence. Lower prevalence rates are reported consistently from low-income countries compared to high-income countries [Loeb & Eide, 2006; Mont, 2007a]. This observation begs several questions. Why are reported prevalence rates of disability so disparate? What are the underlying reasons for the differences seen in disability prevalence rates between low- and high-income countries? What does it tell us about the ‘culture’ of disability in a population? And what can it tell us about disability vis-à-vis social inclusion and/or exclusion?

I have previously attested to several possible reasons for the prevalence discrepancy [see Loeb & Eide, 2006] and it is worth re-visiting and expanding upon those here.

2.1 Choice of model (medical versus social)

Observed lower disability prevalence rates reported from some low-income countries tend to reflect the most severe cases of disability in the population as is evidenced, in part, by the method of measurement. Several low-income countries have employed a medical model approach to the measurement of disability that focuses on the individual's physical/mental impairment or “type of disability”. This operationalisation is captured with questions like those used in the Zambian census of 1990 and still used in several censuses and surveys today: Are you disabled in any way? (Yes/No) and What is your disability? Blind, Deaf/Dumb, Crippled, or Mentally retarded. [Loeb et al, 2008]

Coincident with the impairment-based approach that likens disability to the *outcome* of functional difficulty on body function and structure (i.e. blind, deaf etc.), disability has also, in some surveys, been linked to *diagnosable* conditions – associating disability to *cause*. Classifying disability this way may also result in under-reporting and lower prevalence since many people without access to basic health care, or those with some intellectual/mental and psycho-social conditions may not know their medical diagnosis. As a contributing

environmental contextual factor, access to health care services, can vary widely and, untreated diabetes, for example, can lead to profound functional limitations such as blindness or mobility limitations due to the loss of limbs, while diabetes under proper management can have a relatively minor impact on someone's life. [Mont, 2007a]

Questions that focus on basic actions [Madans et al, 2004], like those proposed by the Washington Group on Disability Statistics (see below), serve as a better basis for identifying disability and result in prevalence rates that are not only higher, but are more suited to capture some of the complexity of disability. The social model approach to measuring disability focuses on the limitation of activity and the restrictions of participation, and the medical or health condition becomes the underlying cause – not the basis for definition. For example, a question that focuses on a basic action like lower body functioning: *Do you have difficulty walking or climbing steps?* is able to identify mobility limitations resulting not only from paralysis or amputation, but also serious heart problems or other medical conditions that may be associated with vision or balance that impact mobility for example. Similarly, the question *Do you have difficulty communicating?* can identify limitations associated with stuttering, loss of speech due to stroke, autism, or a number of other conditions. For purposes of determining social participation and the equalisation of opportunities, the functional status of an individual – and how that impacts their life – is of interest and not necessarily the cause (medical or otherwise).

A social model approach to measuring disability that focuses on the limitation of activity and incorporates multiple response options (no difficulty, some difficulty, a lot of difficulty and cannot do at all) is not restricted to an imposed dichotomy (Yes/No). This type of operationalisation allows for the derivation of a range of disability prevalence rates encompassing mild, moderate and severe levels of functional difficulty. Choosing a disability threshold at “cannot do at all” would be the same as a response of *blind* to the impairment question above, both indicative of severe disability. Nothing is lost with this social model approach – and much is gained.

2.2 Lack of a neutral language

The historic lack of a neutral language to describe and define disability has also had an impact on how disability is perceived in some cultures. According to Mont [2007a], in some cultures the word “disability” may suggest negative associations and some people in these cultures may be reluctant to self-identify as disabled, feeling stigma or shame. Moreover, to some respondents the term “disability” may be equated with severe or very significant conditions. Persons who can walk around their homes but are incapable of walking to the market may perceive their situation as not severe enough to be considered a disability even though their daily activities are limited.

With the advent of the International Classification of Functioning, Disability and Health (ICF) [WHO, 2001] the disability research community has moved a large step in the direction of a common or neutral language for disability, and a smaller step in the direction of a common means/methodology to measure disability. There remains, however, no gold standard for disability measurement. Nor should we be looking for one. A gold standard or a litmus test (here, that question or set of questions) that would correctly and definitively

classify someone into one or another disability ‘category’ is necessarily absent. Disability is not something that can be simply morphed into a convenient yes/no dichotomy.

The questions developed by the WG do not mention disability but employ rather a more neutral language [WHO, 2001] that focuses on difficulties a person may have doing some basic actions.

Similarly, in some surveys individuals are asked whether they *suffer* from difficulty or disability. *Suffering* may be associated with disease or illness and not necessarily with the life experiences of a person with disability. This language may also negatively influence the self-reporting of functional difficulties [Schneider, 2009].

2.3 Socio-cultural determinants

Another reason for under-reporting of disability may be that individuals did not acknowledge a limitation if they are unaware of the possibility of improving the situation with relatively simple technical aids. In other words, you may not know that you're having difficulty until you experience how easy it is to do the same task with some aid or assistance. This can be addressed in terms of coping mechanisms and the gap between what an individual is able to accomplish and what society demands of the individual – taking into account what may be provided and available in terms of assistance. Perhaps in a low-income, rural culture an individual with a physical or intellectual impairment can contribute to the welfare of their family through *participating* in agrarian activities within the scope of their own abilities and capabilities. In such circumstances, that individual may NOT be considered by family members as having a disability. In the extreme, if there is nothing to read, is the inability to do that activity (as a result of a visual or intellectual impairment) considered a disability? Talle [1995; in Ingstad & Whyte, 1995] claimed that in many aboriginal African cultures disabled individuals are both integrated and accepted. Being identified through family and community or through membership to an age cohort was more important to social identity than was impairment or disability.

On the other hand, in what I refer to as techno-dependent cultures (mostly representing high-income countries) [Loeb et al, 2008] where *time* becomes an important factor in accomplishing a task, the demands of society on the individual are far greater. For example, the inception of the fax machine in the 1980's cut response times to correspondence markedly – and today much inter-personal communication is computer-based, electronic and occurs in real-time with miniscule response-times. In addition, the complexity of *performance* and demands on the individual have grown exponentially with multi-tasking– the ability to handle more than one task at a time. With technological advancements many individuals can rightly claim that they can do much more today in an hour than they could in a day a decade ago. However, the more society or your culture demands of you, the more you need to do in order to perform – to keep up – to meet goals – and consequently, more can go wrong. Humans are finely tuned ‘machines’ and when we become over-stimulated/over-worked, like a machine, we can burn-out – and those of us previously non-disabled may become disabled. Moreover, if people with existing functional difficulties are considered to be at a disadvantage, to be at risk of reduced social participation, then under

these circumstances, their risk is further increased. This type of work disability is not uncommon in high income countries like Norway, Japan and the USA.

To further contrast these two cultural paradigms, Ingstad and Whyte [1995] put it this way: '...unlike Euro-American societies, where disability exists within a framework of state, legal, economic and bio-medical institutions, such institutional infrastructure exists only sparingly in developing countries. In these countries "disability as a concept and an identity is not an explicit cultural concept. The meaning of impairment must be understood in terms of the cosmology and values and purposes of social life.' [Whyte and Ingstad, 1995; Page 10]

2.4 Definition and (self-)identity

Finally there are two extremes of definition and outcome that may reflect how we define disability and how an individual may self-identify as disabled. Re-visiting the definition of disability, that claims that disability arises from the interaction of an individual's functional status with their physical, cultural, and policy *environments*, it may be claimed that if the *environment* is designed for the full range of human functioning and incorporates appropriate accommodations and supports, then people with a non-normative functional status would not be disabled in the sense that they would be able to fully participate in society – i.e. the ability to "fit in" to society [Mont, 2007b] (not unlike the example above from rural, agrarian cultures). In such circumstances, an individual may not self-identify as disabled – or their family members may not consider them as such.

Similarly, disability may also be interpreted relative to what is considered as normal functioning, and this may vary across cultures or age groups. Elderly people, for example, who experience significant functional limitations may not self-identify as having a disability because, from their perspective, they can function as well as they may expect someone their age to function.

On the other hand, there are those with a disability who, even given the appropriate accommodations and able to fully participate in society, hold on to their 'disability identity' for purposes other than those described here. Disability is in some instances linked to the receipt of financial support by the government in the form of disability grants (to which any individual so 'determined' would be entitled) – or – disability may have associated with it a means of cultural adhesion or belonging as in the deaf community. [Barnartt, 1996] Under these circumstances, even though barriers to participation are overcome affording the individual equalized opportunities, an individual may more readily self-identify as disabled.

3. Disability and the Washington Group on Disability Statistics

In recent years, a functional approach to measuring disability that draws upon the social model of disability has become more standard, and has recently been adopted by the World Health Organisation's International Classification of Functioning, Disability and Health and operationalized through the work of the UN's Washington Group (WG) on Disability Statistics (Mont 2007a, Mont 2007b)

Historically, disability data reported internationally have varied greatly [Loeb & Eide, 2006; Mont, 2007a and see also: http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp]. Across countries and across years within a country reported prevalence rates have fluctuated depending upon the source of the data, the methodology for collecting the data or the questions used to operationalize disability in a census or survey [Loeb & Eide, 2006]. The lack of internationally comparable data on disability has been well documented previously [see Altman, 2001 among others] and was the subject of a UN International Seminar on the Measurement of Disability in 2001 (see: http://unstats.un.org/unsd/disability/Seminar%202001.html). There was a broad consensus at that seminar on the need for statistical and methodological initiatives at an international level to facilitate the measurement of disability and the comparison of data on disability cross-nationally. The Washington Group on Disability Statistics (WG), a United Nations City Group constituted in 2002 under the aegis of the UN Statistical Commission, was tasked with meeting those challenges.

In the area of disability question design, over the course of the past ten years, the WG has:

- Developed and adopted a short set of six questions on functioning that are suitable for censuses [Madans et al, 2004; WG (website); WG, 2008; WG, 2009a); WG, 2010]. The approach endorsed by the WG has been incorporated in the 2008 UN Principles and Recommendations for Population and Housing Censuses [UNSD, 2008]. (See: Section VI-8: Disability Characteristics pages 178-183, and Tabulations on Disability Characteristics pages 292-294; available online at: http://unstats.un.org/unsd/demographic/sources/census/docs/P&R_Rev2.pdf).
- Developed and adopted an extended set of questions on functioning that expands on the six domains covered by the short set, adding questions about age at onset and impact of the difficulty; expands the number of domains covered, including learning, affect, pain and fatigue; and begins to construct the links between functioning in core domains without accommodation, functioning with accommodation, environment and participation [WG, 2012].
- Embarked (in collaboration with UNICEF) upon the development of a set of questions on child functioning and disability. A module of 14 questions has been developed and is currently being cognitively tested in USA and India, with plans for further testing (2013) in Belize and beyond.

Most recently, the World Report on Disability [WHO/WB, 2011] addressing similar concerns regarding internationally comparable disability data, makes specific recommendations that would enhance the availability and quality of data on disability internationally and that, in fact, reflect the approaches taken by the WG. These include, among others, the adoption of the International Classification of Functioning, Disability and Health (ICF) [WHO, 2001] as a framework for the development of questions on disability; improved comparability of data; the development of appropriate tools (both quantitative and qualitative methodologies) to improve and expand data collection on disability; and the collection of national population census data according to the recommendations from the UN Statistical Commission [WHO/WB, 2011].

3.1 Development of an Internationally Comparable Measure for Census

As stated above, the main objective of the WG has been the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys.

Herein lies a dilemma: for many low income countries, the main source of population-based data is the decennial census. And a census is normally constricted in the number of questions that can be included. The inherent complexity of the disablement process defies, by its very nature, capture in a simple, single construct.

Taking into consideration the restrictions placed on censuses, the WG set out to develop a short set of questions that would capture the majority of those with limitations in one or more functional domains. The measures identified were to be comparable cross-nationally and cross-culturally and developed according to the Fundamental Principles of Official Statistics [Statistical Commission, 1994] and in a manner consistent with the ICF [WHO, 2001]. Extensive cognitive and field testing of the question set has shown that they produce internationally comparable data [Miller et al, 2011].

The questions cover six core domains of functioning or basic actions: seeing, hearing, walking, cognition, self-care, and communication. A single question was constructed for each domain.

The next questions ask about difficulties you may have doing certain activities because of a health problem.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

Furthermore, each question has four response options: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. This scale of degree of difficulty is used in the response categories in order to capture the full spectrum of functional difficulty ranging from mild to very severe.

The reader will note that this short set of six domains may appear incomplete; that specific questions on difficulties that relate to intellectual or developmental disability and emotional or psychological difficulties are either absent or limited in scope. The WG short set was designed to be used in national censuses and this objective limited the number and format of the questions. This apparent oversight will be addressed in more detail in the Discussion.

3.2 Determination of disability [WG, 2010]

The WG chose first to focus on core domains of functioning or basic actions since these are considered less likely to be influenced by either specific cultures or the environment, and are thus more suited as international measures capable of providing comparable data cross-nationally. Secondly, basic actions form the building blocks for more complex activities [Altman & Bernstein, 2008]. For example, a complex activity like going to the doctor involves a combination of basic actions and can, in fact, include all 6 of the WG functional domains: mobility, cognition, communication self-care as well as seeing and hearing. While the ideal would be to collect information on all aspects of the disablement process and to identify every person with a functional difficulty within every community, this would not be possible given the limited number of questions that can be asked on a National Census. The basic actions represented in the question set are those that are most often found to limit an individual and result in participation restrictions. Domains were selected using the criteria of simplicity, brevity, universality and comparability. It is expected that the information that results from the use of these questions will, a) represent the majority of, but not all, persons with limitation in basic actions, b) represent the most commonly occurring limitations in basic actions, and c) be able to capture persons with similar problems across countries.

The WG has identified the assessment of equalisation of opportunity as the purpose for measuring disability that can best be achieved in a Census [Madans et al, 2004]. Over the course of time, the Census allows for assessment of equalisation of opportunity by monitoring and evaluating outcomes of anti-discrimination laws and policies, and service and rehabilitation programmes designed to improve and equalise the participation of persons at all levels of functioning in all aspects of life.

In a Census, persons with disabilities are defined as those who are at greater risk than the general population of experiencing limitations in performing specific tasks (activities) or restrictions of participation in society. This group would include persons who experience difficulties in one or more of the six core domains, such as walking or hearing, even if the difficulties they experienced were alleviated by the use of assistive devices, living in a supportive environment or having plentiful resources. Some of these individuals may not experience restrictions in participation such as in shopping, doing household chores, working or going to school, because the necessary adaptations have been made at the level of the person (technical aids, assistive devices or personal assistance) or their environment (physical, social or civic accommodations). They would still, however, be considered to be at greater risk than the general population for participation restrictions because of the presence of difficulties in the six core domains and because, in the absence of their accommodations, their levels of participation would be jeopardised.

3.3 Analytic approaches

At the sixth annual meeting of the Washington Group held in Kampala, Uganda in October 2006 test results from 15 countries were reported and the short set of questions on disability was endorsed by the 23 countries and 5 international agencies in attendance. In 2008 the United Nations Statistical Division (UNSD) presented Principles and Recommendations for Population and Housing Censuses (2nd Revision) [UNSD, 2008]. Among the

recommendations outlined in the document are several that pertain specifically to the measurement of disability and that incorporate the approach taken by WG. (See: Section VI-8: Disability Characteristics pages 178-183, and Tabulations on Disability Characteristics pages 292-294; available online at: http://unstats.un.org/unsd/demographic/sources/census/docs/P&R_Rev2.pdf) [UNSD, 2008].

The six WG questions cover many but not all areas of functioning. Furthermore, the response categories capture a range of severity of the difficulty experienced. Multiple disability scenarios can be described depending on the domain(s) of interest and the choice of severity cut-off. There is more than one way to capture disability through the application of this set of core questions; resulting in not one but several possible population prevalence estimates that will vary in both size and composition.

The WG recommends [WG, 2010] that the following cut-off be used to define the populations with and without disabilities for the purpose of computing disability prevalence rates and reporting to the UNSD for international comparisons:

> The sub-population disabled includes everyone with at least one domain that is coded as a lot of difficulty or cannot do it at all.

This recommendation is not meant as a restriction, and, as will be illustrated below, using the WG approach to disability measurement allows for the analysis of the continuity of disability and a full assessment of disability in a population by different levels of severity.

4. International comparability

At its inception, certain goals were identified for the WG. Among them, to foster international cooperation in the area of health and disability statistics, to develop a short set of general disability measures suitable for censuses and to untangle the web of confusing and conflicting disability estimates and to produce internationally tested measures for use to monitor status of disabled populations. By standardising these questions it was believed to be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources.

The WG routinely monitors the collection of disability data internationally, and annually requests detailed information from representatives from National Statistical Offices covering survey periodicity, sample size and frame, mode of data collection, language(s) used, the actual questions operationalized with response options and finally prevalence data.

Recently, about 30 countries indicated to the WG that they intended to use the short set of questions on this current (2010) round of censuses. We saw this as an opportunity to follow-up on the implementation of the questions in practice. We sought to collect information from all countries that were using the WG short set of questions (or not) and catalogue the actual questions used and response options applied; the year of data collection and the purpose (census or survey); and the prevalence of disability derived. We were explicit in our request for the exact wording of the questions in order to determine whether this may have any impact on the results.

Annually approximately 120 countries receive requests to report on national activities that relate to disability statistics. Responses are voluntary – and in the last round, responses (including both those that provided data and those that did not) were received from 48 countries. This represents a response rate of about 40%.

These findings were combined with results from other national data collection initiatives of which we were apprised and that also made use of the Washington Group short set of questions.

Data supplied by the countries diverged in a few important ways: data were reported from both censuses and surveys; some countries reported data that pre-date the 2006 adoption of the WG short set of questions; and there was a clear distinction between countries that took a more medical-model approach to identifying disability on their census or survey (i.e. by listing impairments or types of disability) and those that operationalized a social-model approach (by addressing activity limitations). All data received were included in the assessment to provide a breadth of internationally collected disability data and prevalence rates.

Specifics of the data collected will be presented in a separate publication but some highlights of the results will be presented here. We were able to demonstrate, as was shown previously [Loeb & Eide, 2006; Mont, 2007a], that historically and geographically disability prevalence rates vary greatly. Data were submitted to the WG from across the globe and these spanned several years: from 2000 to 2011. Prevalence rates ranged from 0.4% in the Dominican Republic [2002/census] to 16.6% in New Zealand [2006/survey]. As mentioned earlier, reasons for the disparity observed in disability prevalence rates may be attributed to both the methods used to identifying disability and data collection methodologies. Questions that focus on activity limitations generally produced higher rates that impairment-based questions; and surveys generally produced higher rates than censuses.

The objective of the WG in proposing its approach to disability definition and measurement is not to achieve the highest disability prevalence rate possible, but rather to report the rate that best reflects the situation of persons with disability in the country; according to the WG, those at risk of being restricted in their ability to fully participate in society. And secondly to propose a methodology that could be used internationally to produce disability prevalence rates that could be compared cross-nationally.

We have found that while countries have reported disparate disability prevalence rates; with few exceptions, those that use the WG *as intended* and without modifying either questions or response options (Israel [census/2008]; Aruba [census/2010]; Zambia [survey/2006]; and Maldives [survey/2009) have reported disability prevalence rates that are comparable: 6.4%, 6.9%, 8.5%, and 9.6% respectively. Again it can be noted that prevalence results generated from surveys generally produce higher rates than those generated from a census. This is in part due to the fact that surveys are more often targeted to specific populations and are unrestricted in the number of questions that can be included.

Bangladesh used the WG questions as intended in their 2010 Household Income and Expenditure Survey (HIES) but, by lowering the threshold for disability to include those

who had reported *some difficulty* they have increased the size of the target population and produce a prevalence estimate of 9.1%. Had they used the suggested cut point of *a lot of difficulty or unable to do*, the resultant prevalence rate would have been lower.

In addition a few countries claimed to use the WG questions; however, upon closer examination certain deviations were observed. For example, WG questions preceded by a qualifying or filter question (Oman); response categories that were dichotomised (yes/no) usually associated with a change in the wording of the question (*permanent difficulty* – Panama or *serious difficulty* – USA). In some cases domains have been modified, deleted or added. All of these deviations affect the resultant prevalence rate and subsequently reduce the overall comparability of the results. Furthermore, some uncertainty must be apportioned to the translation of the questions – from the English to the local/national language(s) for the census or survey; and back again when reporting results internationally. It becomes incumbent upon the WG – and others interested in the international comparability of disability data – to ensure not only that translations are accurate but also that they most suitably (for the language in question) correctly capture the *concepts* that are being measured.

5. Implications for disability policy

Policy implications related to the flexibility in this approach to disability may be profound. If service provision is based on the disability prevalence then clearly this would impact on policy, particularly in low-income, developing countries where essential resources and capital are scarce. However, one can ask “What are the implications of developing a policy that provides services for, say, 3 % of the population (those with more severe impairments) if 10 % (based on difficulty performing in their current environment) require some service?” And, would it not be more appropriate and efficient to provide services to the specific population that requires them. Using the WG approach to disability measurement it is possible to provide data for each functional domain separately and at different levels of severity (i.e. those with mild, moderate or severe difficulty seeing).

Targeting specific sub-populations would be more cost-effective, and would provide for the equitable and efficient delivery of services. With the knowledge that many children with disabilities in low-income countries do not attend school because of vision problems correctable by glasses, policy could be directed to target this specific sub-population, to provide necessary services and to rectify inequalities. A relatively minor and easily correctable functional problem that would have significant debilitating personal consequences could be avoided [WG, 2009a].

The provision of relevant, valid and reliable disability statistics will potentially influence policy in a number of ways. By defining a population at risk of social exclusion through participation restrictions, early interventions can be initiated to prevent, for example, at risk children from dropping out of school. A rather modest preventative investment in technical aides may allow these children to complete their education, achieve the twin goals of employment and independence, and ultimately become net contributors to society. Furthermore, these data will provide the evidence, over time, that targets set through, for

example Millennium Development Goals or the UN Convention on the Rights of Persons with Disability are being addressed and met.

6. Conclusions

With the data that have been presented here, we shown that the WG has been successful in fostering international cooperation in the area of health and disability statistics through the development and implementation of a short set of general disability measures suitable for censuses and surveys. Working collaboratively with many countries from all regions of the world, the WG was able to develop and test questions for use in censuses and surveys to produce internationally comparable data. The short set provides a comparable mechanism for identifying a population at risk for restrictions in the ability to fully participate in society due to functional limitations in key domains; an approach that has been incorporated into the UN Principles and Recommendations for Population and Housing Censuses [UNSD, 2008].

In so doing we have taken an important step in untangling the web of confusing and conflicting disability estimates and producing internationally tested measures for use to monitor status of disabled populations. We have illustrated the importance of careful translation and operationalisation of the concepts put forward by the WG; and, when adopted as intended this standardised set of questions was able to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources.

A major challenge faced by the WG in developing the short set of questions was to attempt to capture the complexity of disability in a parsimonious manner. The WG has acknowledged that the six questions do not cover all functional domains equally well. Specific questions on upper body functioning, difficulties that relate to intellectual or developmental disability (other than those related to remembering and concentrating) and emotional or psychological difficulties are either absent or limited in scope. The WG short set was designed to be used in national censuses and this objective limited the number and format of the questions. The functional domains represented in the short question set, selected using the criteria of simplicity, brevity, universality and comparability, are those that have most often been found to limit an individual and result in participation restrictions [Madans et al, 2004; Altman & Bernstein, 2008]. The WG expects that the information that results from the use of these questions will, a) represent the majority of, but not all, persons with limitation in basic activities, b) represent the most commonly occurring limitations in basic actions, and c) be able to capture persons with similar problems across countries [WG, 2008]. Currently approximately 30 countries have indicated that they intend to use the WG short set of questions on this current round of censuses. The WG short set of questions has also recently been added to the National Health Interview Survey (NHIS) in the United States. Data analyses pairing the WG short set with other more detailed measures of functioning and health on the NHIS are currently on-going.

Many of the steps taken by the WG in the development of questions on disability have been acknowledged in the World Report on Disability [WHO/WB, 2011:45-47] which recommended the adoption of the ICF, the call for improved national disability statistics and

improved comparability of data, as well as the development of appropriate tools (both quantitative and qualitative methodologies) to improve and expand data collection on disability. According to the World Report on Disability, in order to improve national disability statistics it is important that the routine collection of disability data become incorporated into national disability programs. The Report notes that the short set of questions developed by the WG provides a core set that can be expanded to meet country needs.

Finally, by fulfilling the specific purpose for which the WG disability measure was developed, that is, the equalisation of opportunity and the extent to which persons with disability participate fully in society, the WG short set questions will contribute to monitoring whether, over time, the objectives of the UN Convention on the Rights of Persons with Disabilities have been achieved [WG, 2009b].

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